

V103

# A Compassionate Response to a Request to Die

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## CME EDUCATIONAL OBJECTIVES

1. Beyond empathy and compassion, describe additional professional skill sets that are commonly needed to provide compassionate care for chronically ill patients.
2. Articulate reasons why an anguished expression of, "Please let me die!" may not represent a patient's reflective moral decision.
3. Describe how a patient's important values and core identities can be discerned out of brief intermittent observations of the patient responding to the adversities of illness.

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Among psychiatric consultants, few challenges are as daunting as being asked to evaluate the suicide risk of and to treat the depression in a hospitalized elderly patient who has asked a medical team to "just let me die," particularly when the medical treatment has reached a point of evident futility.

Examination of such a consultation by a resident beginning her psychiatry residency helps clarify some of the skill sets that psychiatric education ought to provide:

- How to respond to a patient's stated desire to be "allowed" to die.
- How to distinguish depression from other syndromes of distress.
- How to assess rapidly a patient's important values and identity, so valid moral reasoning about living and dying can be conducted.
- How to engage a patient's family in medical decision-making in a manner that provides physical care and emotional support, while also respecting the patient's autonomy.

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Psychiatric education must commit to providing its residents with these and other skill sets beyond a narrow focus on diagnosing and treating psychiatric disorders if residents are to become competent and transformative agents of compassionate care.

### A RESIDENT'S PERSPECTIVE

While on a rotation in Geriatrics, I was asked to see a classic "LOL"—a Little Old Lady.<sup>1</sup> Mrs. K, age 98 years, had been admitted for belly pain. Although the pain resolved, the doctors meanwhile found that her long-standing chronic obstructive pulmonary disorder (COPD) had given way to yet another baby pneumonia hiding in the crevice of her left lung. Azithromycin charged to the rescue.

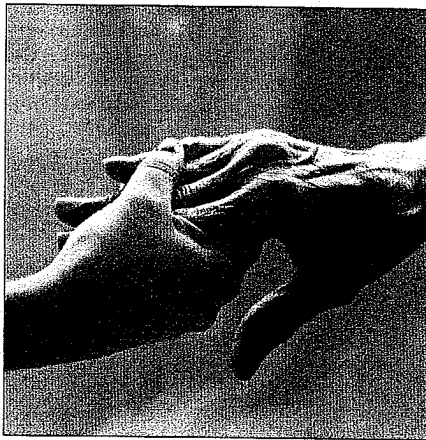
She also reported two "lumps in her neck." Since the doctors weren't sure what they were, and they didn't feel like lymph nodes, they ordered a head and neck computed tomography (CT) scan. The diagnosis: Sialadenitis. Clindamycin now became the savior.

Mrs. K began to complain, "I can't swallow all these pills. I can barely swallow my food." The doctors noted, "Oh yes, you have lost about 20 pounds in the past 3 months. Well, would you be interested in artificial feeding? We could put a tube in your stomach and feed you that way." Mrs. K shook her head, "No. I just want to die," she said softly. "Just let me die." The medicine team then requested the psychiatry consultation-liaison service to evaluate Mrs. K for depression and possible suicidal ideation.

From my conversation with Mrs. K, it became clear that she had no intention of attempting suicide. She just didn't have the will, or the energy, to keep living. Although she had some symptoms of depression, she did not appear to be severely distressed. She looked me in the eye and said, "I'm done here. I just want you to let me go when the time comes. Stop fussing around." Upon discussion, she agreed to try an antidepressant, to see if it might help

her feel better, and that we would continue to discuss her thoughts about dying.

As a PGY-II psychiatry resident, Mrs. K's situation made me aware of my own struggle finding words to talk about death. With plenty of experience evaluating suicidal ideation in an emergency setting, I already had no trouble assessing an actively suicidal patient. But with those who are terminally ill and suffering, or



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have recovered medically yet have decided that the end of their lives are drawing near, I wondered, how do I as a psychiatrist distinguish depression that clouds one's reasoning, from a lucid decision that one is at peace with death?

Mrs. K firmly expressed that she had no qualms about dying. "I have lived my life, raised five children on my own, taken the beatings of an alcoholic husband, and survived. I even called the cops on him finally. He was jailed for 5 years. My children are well settled. Heck, they don't even think to call me, except for Jerry, my youngest son. I was living alone, but after my last pneumonia I got weaker. I can't

really take care of myself anymore so Jerry asked me to come live with him. I did. It's been better. But I don't want to burden him. Children should be able to live their own lives. I can already see the extra work his wife has to do to care for me. But it's not even that. I'm tired. I have nothing else to live for."

"It seems like you've been through a lot in your life. What has given you the strength to get this far?" I asked.

"Thinking about God, I guess. I was raised Baptist. Going to church, feeling the love of the people there who are all familiar to me, praying. All of that helped the most, I think." Her face fell. "It's nice moving in with Jerry, having someone to take care of me. But I also don't get to see a lot of my church friends all the way on the other side of the state."

I wanted to say more, to go deeper, but I had three other patients to see. How could I offer comfort and delve into an existential topic in the limited time that I had? Instead, I offered to arrange for a chaplain to visit with her, if she was interested; I felt grateful that mine was among the many hospitals that offer spiritual care services.

"I don't care. You could, I guess," said Mrs. K.

When I saw her next, Mrs. K. expressed some satisfaction with her conversation with the chaplain. She said it gave her comfort to talk about God in her life, and how God would be there for her as she prepared to die. Once again, I struggled with looking at this elderly woman who, other than her emaciated appearance, looked physically well. Yet she clearly had decided it was her time to prepare herself for death.

We began to discuss hospice care with Mrs. K and her son, Jerry. Jerry was open to considering hospice, if that were to be his mother's wishes. Suddenly, a collection of long-lost children, nieces, and nephews appeared around Mrs. K. After long debates among family members, too long for a tired 98-year-old woman to

win, the relatives triumphantly emerged to tell the primary medicine team, "We want her to go to rehab. She agreed to try it, to get her strength back. We told her that there is nothing wrong with her. She's giving up too soon. She's perfectly healthy, that woman."

One nurse on the treatment team asked the family, "What about what she wants? She has full capacity to make her own decisions, you know." All the while, I watched Mrs. K get paler, her cheeks hollower, her eyes dimmer.

Ms. K admitted to me one afternoon that she had given in to her family out of guilt; she wondered if it was selfish to want to die when her family wanted her to live. We encouraged her to try rehabilitation if that was her decision, but that there was no shame in saying "enough" when it was so. She nodded, and looked relieved. Soon after, Mrs. K was transferred to rehab, having recovered from her pneumonia.

### COMPASSION AND PROFESSIONAL EXPERTISE

Empathy and compassion are the heart of humanistic psychiatry. Yet this resident's frustration, feelings of impotence, and guilt are also palpable. As a PGY-II resident, she felt disempowered witnessing Mrs. K's distress. She grasped Mrs. K's experience and life situation, but felt helpless to reduce her suffering.<sup>2</sup>

Compassionate care requires more than compassion. It also requires professional expertise. The resident felt obligated to respond to Mrs. K's struggle, but did so without the benefit of training she would later receive in psychotherapeutic interventions for medically ill patients, their families, and their systems of care.

As Cruess and Cruess have pointed out, physicians are both healers and professionals.<sup>3</sup> As a healer, a psychiatrist listens to patients compassionately, with respect and authenticity. As a professional, a psychiatrist brings evidence-based expertise to effectively treat psychiatric illness and ameliorate human suffering. This

resident's story indicates which additional skills the remainder of her psychiatric training might provide, such as:

- How to respond when a patient states a wish to die.
- How to distinguish depression from other kinds of distress.
- How to discern a patient's important values and identity when illness and its treatments permit only brief, disjointed, and incomplete conversations.
- How to involve a family in a patient's decision-making about health care.

### ANGUISHED CRIES ARE NOT MORAL DECISIONS

Nearly a century ago, German philosopher Jurgen Habermas put forward the "ideal speech situation" as his standard for conversations, the conclusions of which could be regarded as objectively true.<sup>4</sup> Based upon principles of justice, an ideal speech situation is one in which each participant can speak without fear or coercion and with confidence that his or her voice will be heard, understood, and seriously considered within a reflective dialogue. Many clinicians experienced in hospitals and other systems of care know how far afield from Habermas's ideal speech situation are most clinician-patient conversations upon which patient care is based. Too often the physical pain, isolation, uncertainty, and metabolic encephalopathy during hospitalization closely approximate conditions of torture. Under such conditions, a patient does not speak reflectively, but only as someone seeking to make pain stop. The task for a psychiatric consultant is to create contexts in which needed reflective dialogue becomes doable.

Mrs. K's "I just want to die," is a cry of distress. Such distress ought to mobilize clinicians to prioritize relieving her suffering, even if that overshadows treatment of her disease. The mission of palliative care, whether or not a patient is terminally ill, entails:

- Relieving physical discomfort such as pain, nausea, insomnia, pruritus, or any other physiological source of suffering.
- Treating any psychiatric disorder that compromises cognitive or emotional processing.
- Relieving psychological and social suffering precipitated by illness such as loneliness, confusion, helplessness, guilt, shame, and humiliation.

Until emphasis has been shifted from care-of-disease to care-of-person, it is premature to hear Mrs. K's plaintive "Just let me die" as anything more than a marker of distress. The psychiatry resident shifted her own response to Mrs. K, but the treatment team initially did not accompany her. As the case proceeded, however, the treatment team's focus also began to shift, with its openness to consultation from the spiritual care service, a recommendation for hospice, and an effort to engage Mrs. K's family in her care.

### DEPRESSION VS OTHER KINDS OF DISTRESS

American psychiatry has focused far too little on the importance of distinguishing depression from normal syndromes of distress, especially among the elderly.<sup>5,6</sup> Depression is a psychiatric illness that can so impair a patient's cognitive and emotional capacities as to render a patient incompetent to make medical decisions. Even when less severe, it hinders coping, adds disability, and amplifies emotional suffering.

Depression is highly treatable; recognition and treatment of it in medically ill patients is a high priority. If Mrs. K were primarily depressed, then her claim, "I'm tired. I have nothing else to live for," should be heard as a symptom to be treated. However, demoralization, grief, spiritual anguish, loneliness, and loss of dignity must be distinguished from depression. These and other syndromes of distress represent normal human re-

## SIDEBAR

**Family Meeting Plan<sup>12</sup>****I. Gather and Greet the Family**

- Welcome each member and make a personal connection.
- Learn about the family's identity: What have been the strengths of your family over the years? Are there things you would want me to appreciate about your family?
- State the purpose and meaning of the family meeting, eg, "Mrs. K has faced a difficult course of illness. She needs your help in making decisions about where her care should go from here."

**II. Family Psychoeducation**

- Learn what each family member knows about the patient's illness and its etiology, course, treatment recommendations, and prognosis.
- Provide any needed medical information, clarification, or factual corrections.

**III. Family Assessment**

- Learn if there are impending events in family members' individual lives, or in the family as a whole, that predictably will affect the availability of family support, eg, a retirement, new baby, or grandchild leaving for college.
- When important decisions are to be made, who usually participates and how is the matter handled according to family hierarchy, roles, and boundaries?
- Learn which family members have been most involved in the patient's health care.
- Note whether family members easily collaborate in the patient's care, or whether the family appears divided into different camps or coalitions around important issues.

**IV. Guided Discussion of Key Question**

- Address the question that prompted the call for a family meeting: "Intensive treatment of the patient's pulmonary and gastrointestinal problems appears to be inflicting additional suffering without the promise of a cure or long-term improvement. Would the family support or oppose a recommendation for hospice care?"
- In the spirit of Habermas's ideal speech situation:
  - Determine how the patient should participate in the meeting according to her capacity to process its information: full participation, listening as an observer, or absent.
  - Ensure each person in turn is heard, understood, and given serious consideration with a slowly paced, thoughtful dialogue.

**VI. Summarize the Family's Decision, But Add Needed Complexity and Qualification to the Decision**

- Ask, what would be subsequent indicators that the decision made in this meeting had been a wise or unwise one? How would that be determined? When should it be re-assessed?
- How will each family member commit to subsequent involvement in the patient's care?
- How should subsequent decisions regarding the patient's health care be handled?

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sponses to adversities and should not be regarded as psychiatric illnesses. Moreover, they require fundamentally different kinds of interventions and fail to respond to antidepressants.<sup>5,7-10</sup>

While methods for distinguishing depression from a normal syndrome of distress are imprecise, the following seven questions can provide a "preponderance

of evidence" for determining how a patient's distress ought to be regarded.<sup>5-7,10</sup>

**Did Onset of Emotional Distress Sharply Coincide With Onset or Exacerbation of the Medical Illness?**

Demoralization and grief are immediate responses to adverse events. Depressive disorders, however, often have a chronic

course of illness that has waxed and waned over adult life before, during, and after active episodes of medical illness.

**Is The Intensity of Distress Proportionate to the Severity of Medical Illness?**

The Hamilton Depression Scale provides a quantified measure of depressive symptoms widely regarded as the "gold standard" for diagnosing depression. The Hamilton Depression Scale, or other quantified standardized scales, usually registers scores in the severe range when the problem is major depressive disorder (MDD), but only mild elevations when the problem is demoralization, grief, or other normal syndromes of distress.

**Does Distress Remit When the Illness Improves?**

Hedonic responsiveness, as an intact capacity to feel pleasure or joy, usually endures despite demoralization, grief, or other normal syndrome of distress. "Are you still able to enjoy things? If you receive good news or receive a visit from someone you typically enjoy seeing, are you able to feel happy or joyful?" A patient with MDD commonly has a pervasive loss of a capacity for enjoyment, even when there is good fortune.

**Are There Associated Symptoms of a Mood Disorder, Grief, or Demoralization?**

In MDD, an anguished mood is typically accompanied by such neurovegetative symptoms as poor appetite, no energy, disturbed sleep, loss of libido, and psychomotor retardation. These associated symptoms are usually less prominent during grief or demoralization.

Commonly, depression is associated with guilty ruminations, loss of self-regard, and suicidal ideation; these are symptoms that occur infrequently during grief or demoralization. Rather than the unchanging and pervasive mood of depression, grief often comes in waves.

Patients with grief often describe it as having a sweet, wistful quality and a de-realized sense that “this couldn’t have happened” that are missing in depression.

Demoralization is characterized by a sense of subjective incompetence, as though one is not measuring up expectations; this is not characteristic of depression.

### **Are There Identifiable Biological or Psychosocial Risk Factors for Depression?**

Family history of mental illness, early life emotional abuse or neglect, drug or alcohol abuse, or treatment with mood-stabilizing medications such as steroids, heighten the likelihood that dysphoria represents depression, rather than a normal emotional response to loss or adversity.<sup>7,11</sup>

### **Is There a Past History of a Mood Disorder; Has It Shown a Pattern of Relapse and Recurrence?**

MDD most often has its first onset during teenage years or early adulthood. After that, recurrences occur periodically during adulthood in approximately half of patients. Past history of a severe episode of depression lasting longer than a couple of weeks heightens the likelihood that the current episode is a recurrent mood disorder.<sup>7</sup>

### **Has There Been a Robust Response to a Psychiatric Medication in the Past?**

As a general rule, antidepressant medications have no efficacy for relieving grief, demoralization, or other normal syndromes of distress. A history of dysphoria that responded to an antidepressant in the past heightens the likelihood that the current episode represents a mood disorder.

For Mrs. K, this assessment would have required both additional interview data and collateral information based on observations by her family and nursing staff. If it were depression, then Mrs. K’s distress might have been framed as an illness that

needed to be treated before she should attempt to address decisions about her future.

If it were demoralization, then her distress should have been normalized and her struggle honored: “Given what you’ve gone through, most anyone would feel this way. You have fought valiantly.” For demoralization, all efforts would be

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placed not on treating depression with medication, but on relieving stress and helping her mobilize resources for assertive coping.<sup>8-10</sup> If the data were to suggest both depression and demoralization, then effective treatment would require separate arms to address each.

### **DISCERNMENT OF VALUES AND IDENTITY**

Restoring morale would have meant learning about Mrs. K’s core identity and responding to her as that kind of person. However, it is a challenge to discern a patient’s important values and identity during the throes of severe illness. As the resident reflected, “I wanted to say more, to go deeper, but I had three other patients to see. How do I offer comfort and delve into an existential topic in the limited time that I have?”

It is typically impossible to conduct a thorough psychological evaluation of an acutely ill medical patient. Time allocated for psychiatric consultation is cursory. The patient’s time and attention are focused on the medical treatment. A patient is often too physically ill to conduct a reflective dialogue at any length.

Yet, accurate appraisals of a patient’s important values and core identity can be conducted by observing how the patient responds to her illness.<sup>7,8</sup>

In her spontaneous comments, Mrs. K had already revealed much about her identity. Some of her core beliefs expressed were:

- Mrs. K thrived on relationships in order to cope — “Going to church, feeling the love of the people there who are all familiar to me, praying. All of that helped the most, I think.”
- Contributing to the lives of others was important — “I can’t really take care of myself anymore, so Jerry asked me to come live with him. I did. It’s been better. But I don’t want to burden him with me. Children should be able to live their own lives.”
- She was a Christian. “Thinking about God, I guess. I was raised Baptist. Going to church, feeling the love of the people there who are all familiar to me, praying. All of that helped the most, I think.”
- As is common among survivors of abuse, she would prefer death rather than a trapped existence in which she felt abused or neglected — Mrs. K expressed firmly that she had no qualms about “leaving this earth. I have lived my life, raised five children on my own, taken the beatings of an alcoholic husband, and survived.”

Core identities are reliably revealed by observing how a person responds to extreme adversity.<sup>7,11</sup> A clinician’s task is to listen with a discerning ear, then to follow these observations with a few focused existential questions that clarify and elaborate.<sup>7-11</sup> The resident’s question, “It seems like you’ve been through a lot in your life. What gives you the strength to go forward?” was a well-posed existential question that elicited her clearest image of Mrs. K as a person. Some additional existential

questions, asked gently to this 98-year-old woman, might have further clarified important aspects of her identity:

- For which friendships and relationships have you been most grateful? How did they help you through difficult times?
- What would you have most wanted your children to have learned from your life?
- Do you have regrets? What did they teach you?
- If any of your children were also to live 98 years, what would you most wish for their life to hold in those latter years?
- How has your religious faith helped you during hard times?

### EFFECTIVE FAMILY MEETINGS

Inviting Mrs. K's family into her care was a turn in a more humanistic direction. Families are the primary providers of care for the chronically medically ill. It is likely that Mrs. K would have wanted most to live in intimacy with her family. Yet the family meeting came to an unsatisfactory outcome.

A family meeting requires structure and leadership from the clinician. Families usually have diverse memberships: some family members know more about an ill member's affliction than others; some family members are outspoken and dominating, while others are quiet and submissive; some members are motivated by loyalty and generosity, while others are motivated by resentments, blame, or guilt.

An effective family meeting requires a clinician who controls the structure and process of the meeting while interacting in a collaborative manner that welcomes family members' participation. See Sidebar, page 130, for a prototypic outline for an effective family meeting.<sup>12</sup>

An organized, methodical discussion should set a context in which the patient and each family member can air their concerns and be heard. Everyone should be provided with sufficient knowledge

about the patient's illness and prognosis so that they can make informed decisions. The family meeting should accomplish more than making a "yes" or "no" decision about hospice care. It also should strengthen connections between the patient and family members, affirm and validate the patient's experience, and enlist family members in the practical aspects of subsequent care.

In Mrs. K's case, an effective summary would be: "As a family, you have made it clear that you still need your mother and grandmother with you. You want her to go to rehabilitation and to recover. She indicates that she is willing to do that.

"However, she also is clear that she must not go through it alone. Let's discuss how you will stay close with her during her recovery. I have a sign-up sheet to record when each person here today commits to visiting her during rehabilitation and how you will continue to do that on a regular basis."

### CONCLUSION

Mrs. K has at least three different core identities that do not necessarily coincide — a personal self, a family role self, and a collective self.<sup>13</sup> Mrs. K, from within her heart of hearts (personal self), may well have voiced a wish to leave her life. However, she also was a mother and matriarch (family self) and a Christian (collective self). Deciding which of these identities stands as "who I am" in the particular moment involves profound moral decision-making.

A psychiatric consultant ethically could not make that choice for Mrs. K, but could help to create contexts in which noncoerced, reflective moral reasoning would become possible. One element of that would be to reduce the burden of physical and emotional suffering. Another would be to clarify her important values and core identities. Still another would be to structure family and treatment team interactions so that Mrs. K's voice could be heard by her fam-

ily and treatment team. The psychiatric consultant's role is not only to treat psychiatric illness, but also to shepherd that process to a compassionate conclusion. Psychiatric education must commit to helping its residents develop skill sets that go beyond diagnosing and treating psychiatric disorders if they are to become competent agents of compassionate care. The first task of psychiatric educators is to recruit into our profession committed healers such as the PGY-II resident who treated Mrs. K, whose capacities for empathy, compassion, and bearing witness are already highly developed.

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